

Genetics Task Force Subcommittee Report

Subcommittee Title: The Use of Genetic Information for Other Social Purposes

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I. The incidence of discriminatory actions based upon genetic information

A. Findings

1. The task force received little information on the incidence of discrimination based on genetic information in the state of Washington. Information provided by the Department of Health Genetic Services Section (DOH GSS) includes a few cases in which family history or genetic status appears to have been used to adversely discriminate against an individual.
2. The Washington State Human Rights Commission (WSHRC) reported that no claims of discrimination based on genetic information have been received by the WSHRC.
3. Statistical tables used by life insurance companies inherently contain genetic information.
4. Agencies do not systematically survey people or make proactive efforts to collect information regarding discrimination based on genetic information.
5. Health, life and disability insurers view genetic information as a category of health care/medical information.
6. One committee member believes that current legislation protecting the privacy of medical information does not provide sufficient protection against the misuse of genetic information by employers or insurers. Other committee members disagree. The specific concern is whether the Health Insurance Portability and Accountability Act (HIPAA) or other laws prevent insurance companies from requiring an individual to provide genetic information.

B. Conclusions

1. Evidence of discrimination based on genetic information received by the task force does not suggest widespread problems regarding the use of genetic information for social purposes such as health, life or disability insurance or employment. However, the incidents reported to the DOH GSS are unlikely to represent all such events. Currently, quantitative data on the extent of actual or perceived discrimination based on genetic information is lacking.
2. Existing regulatory policies and practices provide protections against discrimination based on genetic information; in particular, state and federal laws protecting the privacy of health information and limiting the use of health information by employers and insurers provide important

protections (see II.2 below). However, some committee members believe that gaps exist in the protection provided by these existing laws.

3. One committee member recommends legislation to create additional safeguards to prevent employers and insurers from misusing genetic information. Other committee members believe that no additional safeguards are needed.

C. Recommendations

1. The Task Force should seek additional information to enable it to define the protections provided by current law against the misuse of genetic information. Task Force Members should have the opportunity to debate further the need for additional state law that would prohibit the collection and use of genetic information by employers and insurers

II. Strategies to safeguard civil rights and privacy related to genetic information

A. Findings

1. Both state (RCW 70.02) and federal law (HIPAA) protect the privacy of medical records.
2. HIPAA provides no protection for the non-group private sector health insurance market.
3. State laws and industry practice disallow the use of health information (including genetic information) to set rates for, cancel or non-renew a consumer of health insurance. Disability and life insurance may use health information to underwrite a policy but state law and/or industry practice prohibits the use of health information to cancel or non-renew a current consumer of these types of policies.
4. Federal law such as Graham-Leach-Bliley and state laws exist to protect employee's individual privacy rights
5. WSHRC interprets existing state and federal laws to be applicable in cases of employment or other discrimination based on genetic information, however this has not been tested in the courts.
6. The task force received no information documenting the protection of DNA samples taken for court cases or other uses outside of the health care system.
7. One committee member is concerned that the Americans with Disabilities Act (ADA) does not provide blanket protection against discrimination based on genetic information, particularly in light of recent Supreme Court rulings limiting the scope of protection provided by the ADA.

B. Conclusions

1. Existing laws and regulations are sufficient to protect the privacy of medical records.

2. Existing state and federal laws as well as industry practices/policies provide protection for an individual's privacy and civil liberties with respect to health, life, and disability insurance.
3. Existing laws provide protection against employment discrimination or other privacy/civil rights violations.
4. Regulation/oversight of the collection and use of DNA samples for legal or other non-health care purposes may be lacking.

C. Recommendations

1. It is not clear that the state of Washington needs additional laws to protect the privacy and civil rights of individuals with respect to medical records, health/life/disability insurance, or employment.
2. The state of Washington should consider policies to safeguard DNA samples/genetic information collected for legal or non-health care related purposes. Such policies should include informed consent requirements, collection and storage standards, and disclosure guidelines.

III. Remedies to compensate individuals for inappropriate use of genetic information

A. Findings

1. Federal and state laws provide for civil and/or criminal penalties for violations of privacy and/or anti-discrimination laws.

B. Conclusions

1. The existing tort system contains an avenue to compensate individuals for inappropriate use of genetic information.

C. Recommendations

1. It is not clear that any additional action is required by the state.

IV. Incentives for further research and development on the use of DNA to promote public health, safety and welfare.

A. Findings

1. Biotechnology and research endeavors in Washington are sensitive to changes in legislation that may affect their ability to conduct research.
2. The task force heard from several presenters that fear of discrimination is a reason that people do not participate in genetic studies.
3. Research involving human subjects may be subject to different oversight requirements depending on the source of funding/regulation or level of anonymity involved in the data collection process.
4. The newborn screening program is an important public health resource.

B. Conclusions

1. Washington law must be such that biotechnology companies and other researchers would want to locate or continue to remain and operate within the state.

2. Policies are needed to address the perception of the risk of discrimination associated with participating in a genetic research study.
3. Samples collected and stored as part of the newborn screening program should remain available for Institutional Review Board (IRB)/DOH approved research activities.
4. Policies are needed to create a standardized oversight process for research involving human subjects.

C. Recommendations

1. The state implement programs or other processes to educate the public, researchers, employers and health care providers about existing measures to protect an individual's civil liberties and right to privacy. Such a program may reduce the perception that the risk of discrimination is high and encourage people to participate in genetic research.
2. Any process to create policies to address the use of genetic information in research should invite participation from all stakeholders.
3. All research involving human subjects in the state of Washington should be subject to IRB review and oversight consistent with Federal regulatory standards; consideration should be given to the creation of a centralized oversight committee that would coordinate IRB activities and monitor the reporting of adverse effects of genetic information generated by research.